

ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN1907001

Exhibits: WITN1907002

Dated: 31 March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

Section 1. Introduction

1. My name is GRO-B and my date of birth is GRO-B. My address is known to the Inquiry.
2. I currently live alone. I have had three children, one of whom passed away aged 21. My two daughters live in London. I have seven grandchildren.

Section 2. How Infected

3. I was infected with Hepatitis C ("HCV") from a blood transfusion at the Royal Free Hospital on 13 August 1977. My name at the time of the operation was GRO-B.
4. I was pregnant, and was rushed to hospital due to haemorrhaging. An emergency caesarean section was performed on me, which required a transfusion of three units of blood. My doctor was called Dr McCarthy.

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(WITN1907002). I was discharged from hospital with my newborn daughter on
GRO-B 1977.

5. I was not given any information at the time of my operation about the risks of a blood transfusion. It was an emergency surgery required to save my life and that of my daughter.
6. I found out that I had been infected with HCV in February 2007.
7. I had just watched a segment of *This Morning* in which Anita Roddick appeared as a guest to discuss the fact that she had contracted HCV from a blood transfusion. I missed the beginning of the programme and started watching when Anita was talking about how she had felt tired and unwell for years before being diagnosed with HCV. I really identified with the symptoms she was describing – feeling ill, tired and depressed over the years – but I had assumed that I was feeling run down due to caring for three children under five years old.
8. When Anita mentioned at the end of the segment that she had contracted the infection from a blood transfusion, I felt I should have a blood test just to rule out HCV as I knew I had had a blood transfusion during my C section. I certainly did not think the test would be positive, but thought it would give me peace of mind to rule it out.
9. I phoned my GP and made an appointment for a blood test. After the test was done I went back to the surgery for the results, at which point I was told by a stand-in GP (not my usual doctor) that I had HCV.
10. I asked the doctor “what does that mean?” but she could not give me any information about it other than that I should not drink alcohol. She did not tell me what the condition entailed or the dangers of it, or if there was any treatment I could have or anything I should do to prevent it getting worse. She just let me walk out the door without any answers, paralyzed with fear.

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11. I went to the library the next day to search for any information I could find about HCV, as I did not have access to the internet. I could only find one book at the library that discussed HCV, which was very scary as it said that there was no treatment available and that most people died of HCV. I knew the book was old and may not have contained up to date information, but it was the only book that was available at the library. I left the library frightened for my life.
12. I believe that I should have been given information about HCV and how to manage it on the same day that I was given the results of my blood test. It was incredibly irresponsible for the GP to let me walk out of that surgery without any information. Without the internet or any information from medical professionals, I had no way of knowing if there was any treatment available to me or what to expect going forward. I felt distraught and terrified about my future.
13. I was never given any information about the risks of infecting others.
14. Shortly after seeing that GP I made an appointment with my regular GP to go in and discuss my diagnosis. I was then referred to a specialist at our local hospital, GRO-B Hospital in GRO-B, for more blood tests which confirmed the diagnosis.
15. I attended several other hospitals that year to have further tests. I requested to be sent to Norwich Hospital as GRO-B Hospital was very small and didn't offer the same specialist tests. I then attended Chelsea and Westminster Hospital for a fibroscan as the other hospitals did not have this technology. My fibroscan score was 6.4.

Section 3. Other Infections

16. I believe I was infected with Hepatitis A as well as HCV. I was told after a blood test at Chelsea and Westminster Hospital that I had tested positive for

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Hepatitis A, so it had probably been in my system at one point but that I may be immune to it.

Section 4. Consent

17. I do not think I was treated without giving consent or without being adequately informed.

Section 5. Impact

18. The main physical impact of my HCV is that I have been feeling worn out, exhausted and unwell for years and had no idea why until I was diagnosed 30 years after contracting the infection. I always had to have a little sleep during the day, and in about 1989 I had to attend hospital as I was having trouble swallowing. I am now fatigued all the time and there are aches and pains all over my body. I also have memory loss. I itch all the time and my neck and joints are very stiff. There is a chance I may have rheumatism.
19. I thought for 30 years that I was feeling tired and worn down because I was bringing three children up. However, my symptoms did not improve as my children grew older and in fact got much worse over the years.
20. I have been feeling depressed and anxious for many years. I feel like a leper. I am consumed by the diagnosis of having HCV. Every day I wake up I have a fear of dying which seriously impacts on how I live my life. For example, I am afraid of everything I eat just in case it might affect my liver, and have lost a lot of weight due to the stress of this. I am also too anxious to have any treatment for my HCV because I have read about all of the side effects that people have experienced from the available treatments. I am also constantly afraid that someone will find out about my condition and be disgusted to associate with me.

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21. Aside from the symptoms above I have been diagnosed with osteoporosis, myalgia, and tinnitus. I also suffered from global transient amnesia in 2014 which was determined to be from stress.
22. After my fibroscan at the Chelsea and Westminster Hospital, I was told to return to the hospital every 2 years for further fibroscans to see if the condition of my liver had deteriorated.
23. In about 2008 I started attending the Royal Free Hospital for fibroscan and ultrascan tests. My last fibroscan there was in October 2018, and my score was 7.3. I was told that I do not have fibrosis or cirrhosis but I have a fatty liver.
24. The hospital will only test me every two years, however I wish that I could be tested more often. I am GRO-B years old and I am always worried that I could develop cirrhosis suddenly and it would not be caught until it was too late to treat.
25. I have been offered several courses of treatment for HCV, but have refused to have them as I was afraid of having serious side effects or feeling worse after treatment than I did before. I am very sensitive to medication and get stomach aches after taking any tablets, so I am anxious about what might happen to me if I were to undergo treatment.
26. I was first offered a course of ribavirin and interferon around the time of being diagnosed, but declined to have it because I had read about the serious side effects. In addition, I have genotype 3 HCV which I know interferon/ribavirin treatment is not always successful in clearing
27. About four years ago I was offered a drug trial and chose not to participate because I did not want to take a drug that had not been fully approved yet.
28. About two years ago I was offered another course of treatment but declined as I was too frightened of potential side effects.

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29. I do want to have treatment eventually but I'm too scared at the moment. My doctor does inform me regularly about the treatments available to me and I hope to be able to take one at some point so that I can clear the virus.
30. I have not faced any obstacles in obtaining treatment. However, I do feel it is an obstacle that the NHS will only allow me to have a liver scan once every two years, as I am concerned my illness may progress significantly in two years and I will have no way of knowing.
31. I do not feel there are any treatments which should have been made available to me but weren't.
32. I have been treated differently to others because of my HCV status when going to the dentist and optician.
33. I went to a dentist in GRO-B about five years ago who told me that I would have to have the last appointment of the day in order to avoid infecting other patients. I never went back to that dentist again.
34. I also went to an optician about six or seven years ago to have my eyes checked for glaucoma. When I told the optician I had HCV, she put gloves on before examining me. I believe she thought she could catch it from me. I was very upset for weeks after that appointment.
35. My relationship with my children and grandchildren has been really affected by having HCV. Shortly after I was diagnosed I took my children on holiday, as I was afraid I would only have a year to live and wanted to enjoy it. Since then, I have no physical connection with them anymore as I am frightened to kiss or touch them due to the risk of infecting them. I used to always cuddle and kiss my grandchildren but now I am frightened I will infect them, for example if I accidentally cut myself.

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36. I have no social life. I am single and would be afraid to get a partner due to my infection and the associated stigma. I have become reclusive and have lost all of my friends because I don't want them to find out about my condition.
37. I feel disgusted about the idea of anyone finding out I have HCV because of the associated stigma. The only people who know about it are my two daughters and one friend, and my daughters rarely speak about it to me. Even my parents and my brother died without knowing. I don't know how I would manage if anyone found out. I wouldn't be able to live with it.
38. Before I had children, I worked as a typist. I stopped working in 1976 when I had my first child, but went back to work in the evenings in about 1981. However, I had to stop working just a few months after that because I was too exhausted and unwell to continue.
39. I then went back to work again in about 1994 as a cashier, and worked part time until 1997. At that point I had to stop working due to depression, fatigue and pain. I have now not worked for 22 years and have to rely on Employment Support Allowance.
40. If I hadn't been infected, I would have kept working for much longer. Before I left my role as a typist my manager said she'd like to train me for a managerial position. I fully intended to go back to work full time when my children were older but I was not able to due to my HCV symptoms.
41. The impact of HCV on my children and grandchildren has been that they are unable to have a warm, affectionate relationship with me. They visit but I am constantly worried about infecting them or them knowing about my infection. I wish I could share more of myself with them.

Section 6. Treatment/Care/Support

42. I have not had any difficulty obtaining treatment. However, I do wish there had been more support provided to me at the time of my diagnosis. I was not given any information about what to expect or any counselling.
43. I have had two courses of Cognitive Behavioural Therapy (CBT) on the NHS. I had one course in many years ago, and one in about three years ago. I did not find these sessions very helpful because I was only given six sessions in each course and I do not feel CBT is appropriate for this type of topic. I wanted to see a counsellor to talk about how I was feeling and get to the root of my depression, which was not possible with CBT as it is more surface level.
44. I did request to see a counsellor for talk therapy at one point but was told the waiting list was too long. However, when my brother died I was offered bereavement counselling. I don't understand why there was suddenly counselling available for that when there wasn't any for me after finding out I had HCV.

Section 7. Financial Assistance

45. I was told by a doctor at one of the hospitals I went to in 2007 about the possibility of applying for compensation from the Skipton Fund. I believe it may have been the Hospital in but I am not sure.
46. I completed an application for a Stage 1 payment in 2007 and received £20,000 from the Skipton Fund. I had no problems applying and the payment took a few months to receive.
47. In 2016 or 2017, when the scheme was changed to England Infected Blood Support Scheme (EIBSS), I started receiving payments of about £83 a month.

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48. I continued to receive these payments until April 2018, when I applied for Stage 2 compensation from EIBSS. My doctor had to send a letter to EIBSS confirming that my prognosis was that I would not likely clear the infection. I did not have any trouble applying for this either.
49. I started receiving £1,500 a month in April 2018 and still do today. I also receive £500 at Christmas for heating.
50. I believe that the compensation offered over the years should have been higher. Having HCV has been life changing for me and the amount of money I have received does not compensate for that. If I had not been infected, I would have had a normal life, but now I feel my life is over.

Section 8. Other Issues

51. I hope that the Inquiry gets to the truth of what happened. I believe that the NHS knew there was HCV in the blood they were giving us, but still gave it to us. I want to know why they did that.
52. I also cannot understand why the doctors did not tell me that I could have been infected, once they were aware that transfusions in the 1970s contained infected blood and knew I had had a transfusion in 1977. It was a recall and I was never recalled. I was with the same doctor for years and years but they never looked into the possibility that I could have been infected. For 30 years I continued as normal, drinking alcohol whilst socialising and not knowing this could be affecting my liver. I could be dead now if I drank more than I did.
53. I would like to be compensated for what happened. However, no amount of compensation can go back 40 years and give me my life back. I don't know what my future will hold. I don't know when I'm going to get cirrhosis, or how I can continue to live with the anxiety about others finding out about my condition. My life is effectively over. Compensation can make me more comfortable, but can never make up for what happened.

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Statement of Truth

I believe that the facts stated in this written statement are true.

Signed

GRO-B

Dated31/3/19.....